Update on Enhanced Perinatal Surveillance, Toward Elimination of Perinatal HIV Infection: Surveillance Data to Target and Evaluate HIV Prevention Programs —Mary Lou Lindegren, CDC

The book by Walt Dowdle and Don Hopkins, *The Eradication of Infectious Diseases*, discusses the definition and concept of elimination of an infectious disease:

- **Elimination of perinatal HIV infection.** The definition of "elimination" is reduction to zero of the incidence of infections caused by a specific agent in a defined geographic area, as the result of deliberate efforts; continued measures to prevent reestablishment of transmission are required.
- **Elements of an elimination program.** Dr. Dowdle and colleagues stress the need for an elimination program to "initiate surveillance early and use surveillance information to guide program strategy." Use surveillance as information for action. Surveillance was a key component of smallpox and current polio eradication efforts. The quality and intensity of surveillance increases with the stage of elimination.

Background of Perinatal HIV Transmission Reduction (provides the basis of feasibility for elimination)

1994. Use of maternal and neonatal zidovudine (ZDV) in AIDS Clinical Trials Group (ACTG) 076 reduced transmission from 25% to 8%. The Public Health Service (PHS) recommended ZDV to prevent perinatal HIV transmission.

1995 onward. Data from clinical trials, observational cohorts, and state surveillance systems document perinatal HIV transmission as low as 5% with ZDV.

1994 through 1996. Declining perinatally acquired AIDS in the United States. 15% of HIV-infected women did not receive prenatal care [Surveillance to Evaluate Prevention (STEP) data].

1998. Short-course ZDV regimen in late pregnancy and intrapartum reduced transmission by 50% in Thailand. Observational data in New York State (NYS) suggest a reduction in transmission with abbreviated ZDV regimen begun intrapartum or in the first 48 hours of life.

1997 to present. Increasing use of combination antiretroviral therapy (ART) during pregnancy.

1998. Use of elective cesarean section in presence of ZDV therapy reduced rate of HIV transmission to 1% to 2%.

1999. Combination ART that reduces maternal viral load to undetectable levels may lower risk of transmission to <1%. Nevirapine (NVP), once at labor and delivery and to baby, reduced transmission 47% relative to ZDV.

Description of Perinatal HIV/AIDS Surveillance

Perinatal HIV/AIDS surveillance is the ongoing and systematic collection, analysis, dissemination, and use of population-based information on HIV-infected pregnant mothers, perinatally exposed and HIV-infected children, morbidity (AIDS), and mortality. Surveillance data are collected actively by state and local health departments. The data can highlight successes as well as missed opportunities so that successful strategies can be targeted to areas of need.

Uses of Perinatal HIV Surveillance Data

· Monitor the HIV epidemic in women and children.

- Assess resources needed for prevention, care, and social services.
- Target and evaluate effectiveness of perinatal HIV prevention (receipt of prenatal care, HIV testing, ARV therapy, other interventions to reduce perinatal transmission, HIV status of baby, follow-up care).
- Evaluate implementation of other public health recommendations such as for *Pneumocystis carinii* pneumonia (PCP) prophylaxis, timely HIV diagnosis and treatment.
- Facilitate evaluation of adverse effects of perinatal exposure to ART.

Types of Perinatal HIV Surveillance Data Collected

- Demographic characteristics
- Maternal prenatal care use, testing history, risk, antiretroviral use (ZDV use during pregnancy, week started, labor/delivery), and other antiretroviral use during pregnancy and labor/delivery
- Neonatal ZDV, other antiretroviral therapy, PCP prophylaxis
- Birth history (type of delivery, prematurity, birth weight, birth defects)
- HIV diagnostic and immunologic tests, opportunistic illnesses, mortality

CDC-Perinatal Prevention Plan, Ryan White Care Act 1996

$10 million was appropriated for perinatal HIV elimination activities.

- $6 million to 16 state and local health departments for program activity through the prevention cooperative agreements
- $1.8 to 26 state and local health departments working on enhanced perinatal surveillance
- $1 million to 5 national organizations
- Collaboration needed with HIV prevention, HIV surveillance, MCH, and substance abuse programs

Enhanced Perinatal HIV Surveillance

- Thirty-two states currently have named HIV reporting. Enhanced perinatal surveillance is an expansion of STEP, a surveillance project initially implemented in four states (NJ, SC, MI, LA) in 1996, which was instrumental in the recent Institute of Medicine Report (IOM) findings.
- Enhanced ascertainment of mother-infant pairs: active case finding at pediatric sites and OB hospitals, matching of HIV/AIDS registry to birth registry, laboratory reporting, and women pregnant at the time of report
- Systematic ascertainment of data from multiple sources: maternal HIV clinic, prenatal, labor/delivery, newborn and pediatric records, standard case report form and supplemental data collection form, active follow-up of exposed infants every 6 months for infection status
- Collaboration with programs (HIV prevention, MCH, substance abuse)

States Without HIV Surveillance

- Alternate methods to collect data on HIV-infected mothers and their newborns—facility-based collection of enhanced perinatal HIV surveillance data, with Institutional Review Board (IRB) approval at those facilities
- Standard case report form and supplemental data collected on HIV-infected mothers and exposed children at those selected facilities (prenatal care, HIV testing, ART)
- Ascertainment of data on perinatal AIDS cases—reasons for failures statewide

- Collaboration with programs (HIV prevention, MCH, substance abuse)

Characterizing the Local Perinatal HIV Epidemic and the Impact of Prevention, Using HIV and All Available Sources of Surveillance Data

- Prenatal care
- General population [birth certificates, Pregnancy Risk Assessment Monitoring System (PRAMS)]
- HIV-infected women (enhanced perinatal HIV surveillance)
- HIV counseling and testing
- All pregnant women (birth certificates, PRAMS, audit of hospital prenatal records at EIP sites)
- HIV-infected women (enhanced perinatal HIV surveillance)
- Use of antiretroviral therapy—ART, enhanced perinatal HIV surveillance, Survey of Childbearing Women (SCBW)
- Outcome of child (enhanced perinatal HIV surveillance)
- Other sources [Medicaid, Supplement to AIDS Surveillance (SHAS), HIV counseling and testing, PSD]

General Perinatal HIV Prevention Surveillance Data

- The number of women living with AIDS is increasing, from 15% (1992) to 20% (1998). The number of women ages 15-34 living with HIV infection is up to fivefold higher than the number living with AIDS in some areas, based on HIV surveillance data.
- The epidemic has especially affected minority populations.
  AIDS cases in adult/adolescent women (N = 10,998) rates per 100,000 by race/ethnicity
  White, not Hispanic = 2
  Black, not Hispanic = 50
  Hispanic = 17
  Asian/Pacific Islander = 1
  American Indian/Alaska Native = 4
- The Survey of Childbearing Women (SCBW) estimated that 6,000-7,000 HIV-positive women deliver infants each year in the United States.
- In order for a prevention success to occur, an HIV-positive woman has to be in prenatal care, be offered and accept HIV counseling and testing, be offered and accept ZDV, adhere to the regimen, and receive follow-up care for herself and her baby.
- The number of perinatally acquired AIDS cases increased from 1989 until a peak in 1992, then declined rapidly after 1994 (ACTG 076), with a 74% decline from 1993 to 1995.

The question is: Can more cases be prevented? Let's look at examples of enhanced perinatal surveillance data.

Selected Surveillance Findings, by Project

STEP. Original STEP data from NJ, LA, SC, MI were critical for the Institute of Medicine (IOM) report and many prevention programs.

- Compared with the SCBW, enhanced perinatal surveillance ascertained over 85% of the estimated mother-infant pairs, which is a very complete surveillance system.
- Prenatal care was found to be less commonly received by HIV-infected women diagnosed during pregnancy (2%) than by the general population (15%).

- Prenatal care by race/ethnicity reflects the general population.
- 35% of HIV-infected women who used illicit drugs during pregnancy did not receive prenatal care compared with 6% who did not.
- Lack of prenatal care during the first pregnancy predicts lack of prenatal care in subsequent pregnancies, according to data in STEP.
- In Connecticut, many HIV-infected women who did get prenatal care received very few visits; 82% of the HIV-positive women received their prenatal care in a clinic and only 4% in private offices.
- The proportion of HIV-infected women tested before delivery was 68% in 1993 and increased to 81% in 1996.
- Proportions of HIV-infected women receiving prenatal, intrapartum, and neonatal ZDV increased dramatically from 1993 to 1996. Very few (<5%) refused ZDV when offered.

Other Findings from Perinatal HIV Surveillance Data in 32 States

- Of children born to HIV-infected mothers and reported to CDC in 1998, the mother was tested before or at birth in only 34% of children with perinatally acquired AIDS, compared with 89% of HIV-exposed children and 61% of HIV-infected children.
- Increasing numbers of mothers who were tested for HIV before the child's birth received any ZDV—over 85% among births in 1998—and increasing numbers of women are receiving other ART in pregnancy—almost 40% in 1998.
- Data from Louisiana highlighted that most HIV-infected women who received prenatal care also received some form of therapy. Prenatal care and ZDV use are associated.
- Data from South Carolina showed that an STD diagnosis during pregnancy or illicit drug use during pregnancy are predictors of receipt of ZDV; thus, STD clinics may be a target for prevention activities in some areas.
- The proportion of HIV-infected children decreased dramatically from 1993 to1997.
- Data from special perinatal HIV surveillance project in New York City indicate that only 7% of children born to mothers who received ZDV prenatally were HIV-infected children compared with 21% born to those who did not.
- Data from NYS indicate that intrapartum and newborn ZDV prophylaxis may be protective as well.

Pregnancy Risk Assessment Monitoring System. PRAMS is a CDC-funded population-based surveillance system of women giving birth. It is administered through the Division of Reproductive Health, covering not only HIV but other risk factors as well. Once in prenatal care, a woman needs to be offered and accept HIV testing. In 1996, the percent of women who in 11 states discussed HIV testing with a health care worker ranged from 60% to 84%. Once offered, most accepted. By 1998, trends in HIV counseling and testing increased, significantly in some states. Prenatal HIV test counseling in seven states increased from 69.7% in 1996 to 77.6% in 1998.

Behavioral Risk Factor Surveillance System. BRFSS is a CDC telephone survey of adults 18 years and older, conducted from 1994 through 1997. Among pregnant women, the proportion tested in 1996 (53%) was significantly higher than in 1995 (41%); there was no significant change from 1996 to 1997. Among women who were not pregnant, there was no change over time.

Connecticut

- Data from perinatal HIV surveillance indicate that not only do pregnant HIV-infected women tend not to receive prenatal care; but the care, once received, is not adequate. Almost 50% of HIV-infected women have fewer than 10 prenatal care visits. Source of care: Most (83%) received prenatal care in hospital-based clinics, making them a place for targeted education efforts.
- Data from a chart review of prenatal care records showed that more women are tested for other infectious diseases (hepatitis B, syphilis, rubella) than for HIV and that HIV testing varies considerably from hospital to hospital.

Perinatal Guidelines Evaluation Project. Reasons for not accepting HIV testing during pregnancy (396 women, 1997)

Reason	Percent
No perceived need for test	42
Previously tested	30
Not asked or test not recommended	8
Other	7
Not ready, too scared	4
Partner HIV-negative	2
Fear of discrimination	1
Scheduling conflict or delivered before test could be performed	2

Epidemiologic Profiles

Surveillance data can be used to create a perinatal epidemiologic profile, which enables one to examine what's going on in communities and target programs, follow programs, and change programs.

- Provide an understanding of the HIV epidemic among populations in the planning region (number of cases, rates, distribution).
- Characterize populations at risk for HIV infection.
- Provide a scientific foundation for the planning process and subsequent steps.
- Perinatal surveillance benefits women's health in general, as the data are applied to other perinatal infectious diseases; e.g., hepatitis B, syphilis, group B streptococci.

Potentials and Challenges for Eliminating Perinatal HIV Transmission in the United States

- Increasing receipt of prenatal care by HIV-positive women, especially substance-users
- Making HIV counseling and voluntary testing the standard of care among all prenatal care providers
- Implementing rapid HIV testing at the time of labor and delivery
- Monitoring the emergence of antiretroviral resistance
- Potential toxicities of antiretroviral drugs
- Improving adherence to complex ART regimens, especially among adolescent women
- Perinatal surveillance to target and evaluate interventions not available in all states